Phantom Loss of Function in Traumatic Brain Injury

Walter S. O. Fo, Ph.D.* and Rosalie K. Tatsuguchi, Ph.D.**

Despite appearing normal, survivors of TBI typically experience residual effects that significantly impact their daily functioning. Informed that they have a mild, transient brain injury which is expected to resolve rapidly, they encounter marked psychological difficulties when their cognitive dysfunction persists. Left undiagnosed and untreated, patients with TBI are at risk of developing serious psychiatric disorders. Early identification and referral to specialists in neuropsychology can head off this adverse clinical course through appropriate assessment and intervention.

Introduction

Traumatic Brain Injury (TBI) is one of the most common of medical conditions afflicting countless millions of people worldwide. Despite its prevalence, it is a disorder that is not widely understood—particularly when clinically manifested in mildly-to-moderately severe presentations of the syndrome. Survivors of TBI often appear uninjured with no obvious physical impairment, yet are unable to resume their normal daily activities due to the residual effects of their brain injury. For this reason, TBI has come to be known as the "silent epidemic"—surreptitiously striking and snatching away productive individuals from the mainstream of society and from personally fulfilling lives.[1]

An Under-Recognized Condition

Many instances of TBI initially may go undetected by health care professionals, despite the presence of medically documented cerebral concussion or other evidence of physical assault to the brain. Even when recognized and diagnosed in a timely manner, the severity of the disorder and its corresponding functional impact upon the individual are frequently underestimated.

When this occurs, the clinical course for patients with TBI becomes unnecessarily difficult and complicated. These patients may be sent home with the pronouncement that they have sustained a mild brain injury which is expected to have minimal effects on day-to-day functioning and to resolve quickly. Further assessment usually is deemed unwarranted, and treatment prescriptions if any are generally palliative in nature. For patients diagnosed with "mild TBI," the reality of their life upon returning home is often a far cry from the innocuous-sounding description of their injury and its accompanying favorable prognosis. To their confusion and dismay, survivors of TBI typically encounter significant functional difficulties in performing what had been the simplest of tasks previously.

Illustrative Case

Ms. S, a 25-year-old single sales clerk, was discharged from the hospital emergency room following a motor vehicle accident in which she sustained a mild concussion. Except for complaints of headache, the patient appeared to exhibit minimal physical sequelae arising from the trauma to her brain. She was discharged home with instructions to follow-up with her primary care provider. Upon seeing her personal physician a week later, Ms. S reported that while her headache had resolved for the most part, she had been feeling listless and fatigued. She complained that virtually everything she did now seemed to be "such a chore." Even the easiest of household work tasks represented a formidable undertaking for her that taxed her mind and sapped her strength. Additionally, Ms. S related how "absent-minded" she had become. For example, she would neglect to use laundry detergent when she did the wash. Repeatedly, she would misplace her keys, or forget what she had gone into a room to retrieve. Ms. S's doctor duly noted her reported difficulties and assured her that while these symptoms were not unexpected, given the head injury that she had sustained, they were likely to be temporary. He encouraged her to be patient and to take things slow and easy for awhile. In the meantime, he would monitor how she was coming along, so she was to return in 2 weeks.

Ms. S's basic clinical presentation did not change substantially when she returned for follow-up, nor did her symptoms remit over the ensuing months. Her husband confirmed that his wife continued to have the same kinds of difficulties in her day-to-day activities as she had reported earlier. Adding to her mounting frustration was the patient's acute awareness that obviously something was terribly wrong with her. She still was not able to perform like she used to. While she had resumed her daily work activities, she found that every task required a substantial effort to accomplish, took longer than usual, and was prone to error.

The patient's arduous efforts to reclaim her prior level of functioning began to exact an emotional and physical toll on her, and she felt demoralized by her life circumstances. She found her condition all

Reprint Requests to:
*Walter S. O. Fo PhD
Chief Psych Consultant
Disability Determination Branch
Division of Vocational Rehabilitation
Department of Human Services
1580 Makaloa Street, Suite 660
Honolulu, Hawaii 96814

**Rosalie K. Tatsuguchi PhD
Clinical Psychologist
Hawaii Institute for Neuropsychology
3221 Waialae Avenue, Suite 378
Honolulu, Hawaii 96816

the more difficult to accept because this "was not supposed to happen," as after all, had she not just sustained a mild concussive syndrome? She struggled to reconcile her daily observations of her own behavior with being told that she had a mild brain injury with transient difficulties that were expected to resolve completely.

By a year post-concussion, Ms. S was a thoroughly exasperated and bewildered young woman. Her symptoms had continued essentially unabated. If anything, they were worse now, as she tended to focus excessively on the difficulties which she was experiencing. She became preoccupied with her deficiencies, which she perceived as rendering her "a shell of the person I used to be." She found herself questioning her own judgment in a wide range of matters, and encountered notable difficulty making decisions. It was perplexing to observe these changes in herself, which served to erode further her sense of self and undermine her confidence. She ruminated obsessively about how drastically her life had changed—and for no real reason or at least one that her doctors could point to!

Compounding the problem, Ms. S began hearing from her family, who were growing increasingly weary and impatient with her, that she was making it difficult for them! They pointed out how irritable she was much of the time, snapping at them for no good reason. She was incessantly demanding and appeared incapable of being appeased. They complained how she was often moody, broke into tears easily, and sometimes flew into rages with minimal provocation on their part.

To Ms. S's consternation, her family also admonished her for "not handling her problems." With her doctors reporting no medical disorder to account for her symptoms and with no obvious physical impairment evident, the patient's family assumed that the problem must be with the patient. They chided her to "change her attitude, stop being that way, and get over it already!"

Not surprisingly, by this time Ms. S was nearly distraught with frustration and anger; clearly, she was exhibiting a significant emotional overlay to her medical condition. In fact, she was at risk of developing a major affective disorder. As far as the patient was concerned, she had already long concluded that she was "going crazy."

Functional Impairment from TBI—Real or Imagined?

Ms. S's case demonstrates what could be called the "phantom loss of function" which often characterizes traumatic brain injury. Like a "phantom," TBI appears not to be there but is actually present. As in the aforementioned case, TBI often presents with accompanying functional impairment which does not seem commensurate with the perceived nature and extent of the brain injury sustained.

This phenomenon occurs because the effects of mild to moderate TBI are often difficult to see on casual observation. Survivors of TBI frequently "look good" on mental status exams, inasmuch as the kinds of difficulties experienced, such as memory problems, are not readily discernible in even carefully performed MSE's. Indeed, standard psychological testing as well may not detect the subtle but significant cognitive deficits associated with TBI. For example, the widely used Wechsler Scales of Intelligence usually do not reliably detect the more subtle aspects of organic brain dysfunction. Moreover, it is not uncommon for patients with serious brain dysfunction to score in the average range on subtests of the Wechsler. Such test findings only serve to obscure, rather than elucidate, the TBI survivor's mental status.

When patients with apparently mild/moderate TBI submit disability claims (e.g., Worker Compensation or Social Security Disability), they may fail to even establish the presence of their disorder, much less demonstrate a severity sufficient to warrant disability status. Many claimants with significant cognitive impairment arising from TBI are routinely denied disability benefits because of a lack of objective findings—despite extensive medical records recounting their complaints over time and an abundance of third-person reports from family and friends corroborating the TBI patient's reported loss of function.

For example, in the Social Security Disability program, it is not uncommon for a claimant's medical records to indicate a less than severe traumatic brain injury, yet the claimant and significant others report a degree of functional limitation which casts serious doubt as to the claimant's ability to perform substantial gainful activity on a sustained basis. This occurs because treatment sources or consultative exams in the medical record report MSE and psycho-

logical tests results which do not substantiate the claimant's allegations with objective findings. In the absence of sufficient confirming evidence from medical sources, a TBI survivor's claim for disability generally is not likely to be allowed. So once again, the societal message to TBI survivors is "You do not have a significant medical condition" in spite of their everyday experience to the contrary.

If the above-described scenario is to be averted, it is essential that TBI be recognized by health care providers at the onset or as early as possible. Just because there are no hard signs of TBI in a particular setting (e.g., in the emergency room or doctor's office), it does not necessarily mean that the condition is not present. Yet it is customary for health care practitioners to assume that if there are no objective indications of a medical disorder, then it must not be present.

Assessment Issues

The following measures may be fruitfully undertaken to ensure the proper identification and assessment of the patient with TBI: (1) Early detection of even seemingly mild cognitive deficits can set the stage for judicious monitoring of the residual functional effects of the TBI over its clinical course. (2) Then when physical sequelae of the brain injury do not remit as expected, further assessment can be undertaken without delay. At that point, preliminary neuropsychological testing can be done to pinpoint more precisely the nature and extent of the cognitive deficits present. Baseline measurements of the individual's current cognitive functioning can be established, to compare with later findings in order to measure changes over time. (3) More extensive neuropsychological assessment may be performed as warranted, in order to produce a systematic brain-mapping of the TBI patient's localized areas of cognitive dysfunction. At the same time, the TBI survivor's cognitive strengths may also be assessed and incorporated into the design of a suitable cognitive rehabilitation plan.

At this juncture in the neuropsychological work-up, it is not unusual for a pattern of cognitive deficits to emerge into focus, which considered singly may not appear remarkable, but collectively yield a compelling explanation as to why the patient with ostensibly mild TBI in fact encounters such pronounced difficulty in daily functioning. By elucidating what is going on in the TBI patient's brain, the results of neuropsychological assessment can be highly instructive to the attending physician, who has now been provided with a framework for making sense of the patient's functional complaints. However, the ultimate value of neuropsychological assessment as a diagnostic as well as treatment tool is perhaps most evident in its positive impact on the TBI survivor, who invariably is in a position to benefit immediately from its findings.

Treatment Considerations

Neuropsychological assessment results typically introduce a measure of light into what had been experienced by the TBI survivor as a veritable darkness. For perhaps the first time since their injury, survivors of TBI are provided with information that accounts for the functional difficulties with which they have lived in past months. The TBI patients' bewildering complex of functional limitations—which heretofore had been experienced as a phantom—now are understood for exactly what they are: logical effects of known causes associated with the specific pattern of cognitive deficits originating from brain injury. These are no longer phantom losses of function, but instead known and expected sequelae of trauma to the brain.

Finally, TBI survivors' everyday life experience in the aftermath of their brain injury is validated. In fact, they have been found to have a legitimate disorder—one that has a name, with residual deficits that can be directly attributed to it. As survivors of TBI come to understand how the brain functions, they acquire a working understanding and appreciation of the specific bases for their cognitive difficulties. Survivors of TBI retrospectively report that attaining this understanding typically represents a turning point for them, like "having a burden lifted off their shoulders." While they still face the same daily functional limitations as before, they reportedly feel better equipped to deal with them. For survivors of TBI, knowledge is power—empowering them to understand and accept their impairment, and ultimately enabling them to cope more effectively.

In addition, the neuropsychological test results afford an opportunity for the family of the TBI survivor to be apprised of the patient's medical condition, including an explanation of the underlying basis for the patient's observed functional difficulties. Proactively providing such information sets the stage for the physician to involve the patient's family more integrally in the treatment plan. Cultivated as allies, caregivers can make a distinct difference in eliciting and supporting the patient's active participation in treatment. Enlisting the family's cooperation in this intentional manner can contribute substantially to improved treatment compliance and outcome—all the while making life a whole lot easier for the physician. At the same time, the attending physician's consultative input to the TBI patient's family members can keep them involved in constructive activities in support of the patient and prevent caregiver burnout.

At this point, the TBI patient's improved prognosis is due not only to a more complete understanding and acceptance of his/her medical condition by both patient and caregivers. It is also attributable to a another concrete benefit of neuropsychological assessment findings—pointing up specific strategies for remediating the cognitive deficits identified. Neuropsychological testing first pinpoints the specific profile of cognitive deficits present, then suggests possible points of intervention for overcoming the individual's identified functional losses.

Misconceptions about Brain Injury

Contrary to popular belief, brain damage is not a condition that either gets better or never does. If one believed this duality of outcome for cases of organic brain dysfunction, one would be reluctant to diagnose those who fell in the cannot-do-anything-for-them-anyway category. In neuropsychological intervention with organic brain dysfunction, an all-or-nothing mentality is decidedly not apropos. Hawaii neuropsychologist James Craine, Ph.D. has made a life's work of developing strategies and techniques for measuring and retraining damaged functions of the brain. His research findings show that neurotraining based on localizing specific cognitive functions can be effective with even severe traumatic brain injuries.[2]

Another common misconception prevalent in the TBI field is that the etiology of a particular organic brain condition determines the nature of the treatment available for it. The reality is that organic dysfunction can be viably treated with intervention techniques linked to the nature and type of the specific cognitive deficit,

irrespective of etiology. For example, the basic cognitive retraining methodologies developed by Dr. Craine, as described earlier, are likely to work with less severe non-traumatic brain injuries and learning disabilities—in addition to severe traumatic brain injuries.[3] These kinds of organic brain dysfunction could not be more different from one another in etiology, yet they may be treated with similar methods of cognitive retraining, based on the localization of brain functions.

Availability of New Treatments for TBI

Thus while still an evolving science and art, neuropsychological training already has much to offer TBI survivors with cognitive dysfunction ranging in severity from mild to marked. However, the availability of effective treatment methodologies for retraining a broad range of organically based cognitive deficits may not be widely known, due to their being relatively new. It may be that if health care professionals were generally more aware of the interventions available for TBI, they might be more predisposed to diagnosing brain damage and informing the patient of it, as well as passing along treatment recommendations.

Timely and well-designed neuropsychological intervention enables TBI survivors to recover certain cognitive functions, by learning to learn all over again. They also are equipped with cognitive retraining strategies for strengthening and re acquiring previously diminished function, as well as for putting into place alternative cognitive strategies to compensate for lost function. The reader is referred to the article on neurotraining by James Craine, Ph.D. elsewhere in this journal edition, which reviews his pioneering research in neuropsychological intervention techniques based on specific, localized cognitive functions derived from careful mapping of the brain.[4]

The Role of the Physician in TBI Management

The process of diagnosing and treating cognitive dysfunction arising from TBI is greatly facilitated by the attending physician who recognizes when to make a timely and appropriate referral for neuropsychological assessment and treatment. The role of the physician in recognizing significant cognitive sequelae of TBI is particularly critical in TBI of mild to moderate severity, in order to avoid some of the pitfalls described earlier. When uncertain, the attending physician may well wish to consider consultation from a neuropsychologist trained and experienced in the assessment and treatment of organically based cognitive dysfunction.

Whether the attending physician manages the patient with TBI alone, or in concert with specialists, it bears noting the obvious: his/her role is a highly influential one in shaping the attitude and expectations of the patient with TBI. This power is naturally double-edged: it can be wielded sensitively and judiciously to impact the TBI patient positively (e.g., to invite the patient to join with the provider in pursuit of his/her own healing or recovery), or otherwise. Obtaining consultation from neuropsychologists, who routinely have expertise in matters of interpersonal influence, can contribute to the development of the kind of working relationship between doctor and patient which optimizes patient outcome. Consultation may also prove fruitful in certain TBI cases in which psychosocial factors may be of such critical importance as to override medical considerations under the purview of the physician.

As an ancillary treatment provider called in to participate in the care of a TBI survivor, the neuropsychologist can contribute significantly to meeting the overall health care needs of the patient. Beyond their expertise in evaluating the presence/severity of cognitive deficits and prescribing treatment for alleviating their effects, the neuropsychology specialist can also play a crucial role in attending to the emotional and psychological needs of TBI survivors in adjusting to their medical condition. Since human organisms are notorious for seeking to make sense of what has happened to them (i.e., by asking such questions as "Why me?" and "What effect will this have on my life?"), any professional guidance provided at such times can have more than salutary impact on the patient with TBI. The specialist in neuropsychology is particularly well-suited to assist the TBI survivor with issues such as these.

Emotional Sequelae of TBI

Patients with TBI who are not afforded the opportunity to talk about their medical condition and its expected impact on their life, or to process their feelings about what has happened to them, are likely to be distracted from full participation in their own health care. As a result, medical compliance issues may needlessly arise and adversely impact the TBI patient's clinical course. The "difficult" or "uncooperative" patient may merely be one who does not understand what is happening to them and is "acting out" their anxieties or other powerful emotions. For the physician who may not discern that the patient is manifesting signs of TBI, it is likely that the patient with mild TBI will be perceived as inexplicably difficult and demanding.

Most prominent among the disruptive emotions which may interfere significantly with the medical treatment of the TBI patient is grief. The patient with TBI is highly likely to be encountering some form of grief over the real and/or perceived sense of loss experienced as a consequence of the functional limitations stemming from the brain injury. The grieving process may be overt, or it may go "underground" where it may not be at all apparent that the patient is in fact grieving. In addition, patients with TBI may suffer from a substantial sense of loss of their "old selves" (i.e., the way they used to be), but they may be in denial and not fully aware of it. Even when acutely cognizant of their sense of loss, survivors of TBI may not understand it or think it is not valid (i.e., justified). When patients sense that what they are feeling or experiencing is somehow wrong or invalid, these feelings tend to be suppressed and hidden, only to make their presence known ultimately by stymieing their medical recovery.

Accordingly, TBI survivors who are actively grieving their loss of function need to be acknowledged in what they are experiencing and their feelings validated, if they are to progress expeditiously through the grieving process. Otherwise, in the absence of a resolution to the patient's grief, bereavement may be unnecessarily prolonged, and along with it, the patient's eventual physical (and emotional) recovery.

While physicians understand that psychological factors may play a key role in affecting a patient's medical condition, they often cannot respond to the emotional needs of the patient within the limitations of a brief office visit. Were they able to do so, or to arrange appropriate referral to psychiatric or psychological specialists, medical compliance and prognosis would be significantly

enhanced. This is particularly true of patients with TBI, who can be especially outrageous in the demands which they make of their health care providers. (E.g., patients with TBI often seem not to comprehend or accept the treatment rationales provided by their doctors for particular medical regimens to which they rigidly and persistently object, or vacillate in their decision-making, resulting in problematic patient management.)

Finally, opportune involvement of a neuropsychologist can prevent the development of psychiatric conditions which can be expected to needlessly hinder the clinical progress of the TBI patient. For example, survivors of TBI who are at risk for manifesting comorbid anxiety or depressive disorders can be properly identified and provided with early psychological intervention. In a similar manner, TBI patients with complaints of cervical pain or headache may receive appropriate psychological attention so as to reduce the chances of their symptoms escalating to a full-blown chronic pain syndrome. Patients afforded timely and appropriate psychological intervention may also be more likely to avoid further physical injury or aggravation of their medical condition.

Conclusion

Traumatic brain injury does not have to be the "silent epidemic" that it has been. Survivors of TBI no longer need to experience their residual loss of cognitive function as a phantom in their lives—invalidating their impairment as well as stealing their dignity and self-respect. An already difficult process of grieving their functional losses and accommodating their medical condition does not need to be exacerbated by denying that a bonafide disorder exists. Survivors of TBI should not have to "go crazy" trying to prove that something is wrong with them. They should not be made to feel that they are "making a big deal out of nothing"—manufacturing or exaggerating their functional problems when no basis for them exists. Patients with TBI should not be stigmatized with the insinuation that they are faking their difficulties or otherwise malingering.

Clearly, when patients with TBI are responded to in this way by health care professionals, progress in treatment is likely to be hindered. TBI patients—like patients with any medical disorder—are prone to become even more preoccupied and invested in their impairments, when their clinical symptomatology is challenged. The predictable outcome is that everyone loses: patients with TBI are likely to persist in their symptoms, for treatment is not likely to be forthcoming for those not even perceived as having a valid medical disorder. The attending physician is likely to be left with a difficult and uncooperative patient on his/her hands. The patient's family is stuck with a family member who is likely to become increasingly hard to live with. And society loses a once productive citizen, whose impairment might very well have been successfully remediated, to the extent of being returned to substantial gainful employment.

In conclusion, a favorable prognosis is more probable if the patient with TBI is recognized early on, ideally beginning with the attending physician, in consultation as necessary with a specialist in neuropsychology. Timely and appropriate neuropsychological assessment can confirm the TBI diagnosis, yield reliable identification of cognitive deficits, and give rise to suitable neurotraining strategies targeting the specific damaged brain functions of the TBI patient. The subsequent clinical course for the patient with TBI is thereby more likely to lead to a positive therapeutic outcome.

Acknowledgment

We thank David J. Lam, PhD for his helpful editorial suggestions and critical review of the manuscript.

Achieving Better Outcomes for Hawaii's Children

Continued From Page 617

In exchange for making a commitment to work on outcomes and measuring progress over time, NPR will negotiate with appropriate federal agencies to permit more flexible use of funds at the state level through less restrictive regulations. This helps states make the most of federal dollars by allowing spending outside of narrowly defined categories. State agencies, working hand in hand with communities, are encouraged to disperse federal funds so that they can address specific local needs, priorities and support tailor-made solutions to community problems.

The National Performance Review Board is impressed with the broad-based efforts in Hawaii to define important outcomes, particularly with respect to children. The Office of the Governor has been in discussions with Vice President Gore's Office about formalizing an initial partnership agreement with NPR that will focus attention on early childhood outcomes. The Good Beginnings Alliance, a private, non-profit organization with statutory responsibility for coordinating improvements to the early childhood system, will play a major role in advancing the terms of this agreement. By working with public and private agencies as well as local Good Beginnings Councils, the Alliance and its partners will help organize a community-based response to ensuring that young children are safe and living in nurturing environments.

Thus, by achieving more clarity on the important goals we wish to achieve, mobilizing communities and providing greater incentives for collaboration towards achieving these goals, we see opportunities for making a difference in the lives of at-risk children. This three pronged approach gives us hope that maybe we indeed can do more with less.